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To Whom It May Concern:

I just recently received an announcement requesting comment regarding revised medical criteria for evaluating skin disorders. While I realize my


comments come a bit past the deadline, I am sending them anyway as I feel they are pertinent to the issue and worthy of consideration.

The ectodermal dysplasia (ED) syndromes are a large group of conditions, which range from mild to severe in the scope and range of symptoms. It is important to note that individuals within the same syndrome group can vary greatly in terms of the impact of the condition. Hence, I would strongly recommend that any individual affected by a type of ED be considered on the merits of their personal situation. I will further state that most individuals affected by ED syndromes do not meet a criteria indicating an inability to do any substantial gainful activity or marked and severe functional limitations. There are, however, some who do and as such should be eligible for assistance. It is important to note that these are very complex conditions that can be medically as well as psychological challenging which can make evaluation of individual patients challenging.

In my role as Executive Director of this organization, I have seen families whose children do not meet eligibility criteria receive assistance and others who do be denied. I realize that individuals serving in decision-making roles cannot know every nuance of every condition. However, it may be worth their effort to ask a few questions of individuals familiar with conditions like ED prior to making a determination. While I am sympathetic and compassionate for those deserving assistance because of the nature of their condition, I have neither for those individuals who take advantage of the system or use relatively mild conditions as an excuse to do nothing. Clearly, either scenario is possible.

Should you wish to have additional information about the ectodermal dysplasia syndromes, I would be happy to send it to you.

Most sincerely,


Mary Kay Richter
Executive Director
MKR/tbm